

CPASS HAWAII

Community Personal Assistance Services & Supports

A SYSTEMS CHANGE GRANT

"Working for a System of Responsible Choice & Participation"



CPASS COMMUNITY NEWS

A Voyage of Empowerment and Discovery

CPASS SUMMIT 2005

Komo mai kau mapuna hoe

"Dip your paddle in"-Join in the effort

2005 Edition

A Hawaiian voyaging theme welcomed members of the CPASS (Community Personal Assistance Services and Supports) Councils to the first CPASS Summit held recently at the Royal Hawaiian Hotel in Honolulu, Hawaii.

Participants of the day long event were energized by a stirring chant and key note address provided by G. Terry Kanalu Young, Ph.D., who emphasized the importance of family, and our "kuleana" for taking charge of our lives. The "crew" members provided inspiring personal stories during the "Tales of the Sea: Personal Journeys of the CPASS Voyaging Society." The self advocates represented the CPASS State Council and the demonstration sites on Leeward Oahu, Molokai and East Hawaii on the Big Island.

The administrative team supported the options for consumer direc-

tion. Speakers favoring this journey included Acting DOH-DDD Deputy Director Susan Jackson; Representative Dennis Arakaki, Chair of the House committee on Health; David Fray, Chief of the DOH-DD Division; and Mike Tamana, Branch Chief, State of Hawaii DOH-



Self Advocate Panel

DDD Case Management & Information Services Branch. Julie Beckett, the parent who spearheaded the first waiver in the United States, shared her personal "Forecasting the Voyage" that helped us later to make decisions about our future. Kevin Dierks and Eleanor Doi got us "setting our sails" by explaining the support services of a Community Support Guide (CSG), a service that will be offered to self advocate

demonstration site project participants.



Representative Dennis Arakaki; Waynette Cabral

Waynette Cabral, Executive Administrator of the State Council on Developmental Disabilities entertained everyone with a clever "weather report" for the future of CPASS. "We're going to keep focused and paddle in sync for smooth sailing to a Consumer-Directed system. The sails are set, the crew's in the canoe, let's start sailing. Together we will weather any storm."

The CPASS website is coming soon:
www.hawaii.gov/health/disability-services/developmental/cpass-grant/

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**To find out more about CPASS contact your case manager or call us directly at
(808) 956-5827.**

MESSAGE FROM DAVID FRAY

WOW! What a meeting at the CPASS Summit 2005: Voyaging Together. The imagery of the Hokualea was powerful. Dip your paddle in! Together we are voyaging through uncharted waters!

The impact of the CPASS grant on Hawaii is NOT reorganization. It is what academic types call “paradigm shift” or “thinking out of the box” and leads to fundamental change.

The idea is simple. If you give people with disability and their families direct control of government’s resources, they will use those resources more effectively and efficiently.

That simple idea requires a change in thinking for both government employees and persons with disability. Government employees must train and trust people that use government services to be



David Fray, Chief, DOH-DDD

honest and frugal with the resources. Case managers become quality assurance facilitators not just gate keepers. Persons with disability become stronger self-advocates and determine for themselves not just what they need but how they want it done. Families of persons with disability accept responsibility for natural supports and allocating resources for everyone. These fundamental shifts in thinking create collaboration between individuals with disability, between families of persons with

disability and between governmental types like me. No longer will rules prevent common sense. No longer will people with disability be made to feel devalued by condescension. No longer will government feel like the adversary. No longer will we ask for what is not needed. No longer will precious resources be wasted.

It is my belief that CPASS will not be an illusion of progress. Hawaii can be the model for the Nation to create inclusive communities that support people appropriately without waste. CPASS is more than just saving money, but instead using natural supports and consumer control to best utilize taxpayer resources making governmental controls unnecessary.

It is about progress FOR people with disability---grab-your paddle, the voyage is just beginning!

EAST HAWAII SITE COUNCIL

Networking & Communication *by Mary Lou Nelson*

Human understanding is derived from open and honest communications between people who have a respect for the opinions of others, even though they may disagree. Clarity is essential in making a point, so to much tactfulness or “beating around the bush” is not only a waste of time, but in some cases, may be deceiving. Our modern, complex social rules are often misleading. Marketers, advertisers, politicians and media are not the only people who have and use the ability to “spin” a story to avoid specific facts which might be negative to their agendas. There-

fore, the first rule of good communications is to be honest and search for honesty in others, which involves asking questions.

As a first step in communications, let us plan to put together a directory of names, living locals, telephone numbers, e-mail addresses, and any other pertinent information, which will be made available to other self-advocates and their families.

Do you like that idea? If you’d like to join the list, contact me. I will probably be writing this column regularly. So, I will set the example with my listing first.

Mary from Nanawale, Daniel’s mom . College Student, Writer. Love books, Retired.
ProphesyDestined@aol.com

Daniel from Nanawale. Likes to do puzzles. Enjoys riding the Heleon Bus, and talking to people. CPASS member.



Ronit, Daniel, Mary

MESSAGE FROM CPASS STATE ADVISORY COUNCIL CO-CHAIRS



Evan Murakami

We both feel that CPASS has helped us by getting people involved and by working together as a team.

It showed us that if we work together as a team the system will change. It is very important for people with disabilities to believe in themselves, that they can control their lives by making their own choices. In our opinion we feel that all sites are doing a very good job. We also feel that the system will change. It will take some time. Let's continue to follow our dreams and hearts.



Joel Lakins

Sincerely, Your Co-Chairs,
Evan and Joey
Program Supports, Developmental Disabilities Division,
Case Management and Information Services Branch

CONSUMER DIRECTION: SIGNS ON THE VOYAGE

By Kevin Dierks, CPASS Project Trainer

The CPASS journey to explore the uncharted waters of consumer direction has often been compared to a Hawaiian voyaging canoe. Hawaiian sailors had to watch for many dangers on the ocean, such as hidden reefs and surprise storms. They also had signs that showed they were on the right path, like the pull of the current or the colors on the horizon. Consumer Direction also has signs to show we are on the right path.

One sign to watch for is decision making. Are the "consumers," those people that are using services, making decisions on how the system and their lives should look? Are they taking responsibility when things go off course to move things back on track?

Another sign to watch for on our voyage is control. Everyone

has things in their life that they cannot control, but a true consumer makes purchasing and budgeting decisions, and has control over how their service dollars are spent.



New relationships are another sign to watch for in consumer direction. We need to be on the lookout for new supporters on the horizon, including "Community Support Guides", fiscal intermediaries, and community members who may not have been asked to help before. Consumers should also have

more friendships based on mutual interest and preferences.

Last, but not least, we should look for signs of safety. Individuals in consumer direction should feel safer, as a result of careful planning to reduce unnecessary risk. Some monitoring is necessary, but this needs to be developed carefully. Many people have made poor decisions at some time in their life, this should not end their freedom or ability to learn and make new choices. The safety net cannot be too tight or it will become more like a straight jacket.

No one can know exactly what the island of consumer direction will look like, but by staying focused and watching for the signs, we will arrive together soon.

**Working for a System of
Responsible Choice & Participation**

LEEWARD (OAHU) SITE COUNCIL

Tom's Story

By JoAnne Cusmano

My son and I moved to Hawaii from the mainland and upon arrival I knew I needed to find resources for services, but where should I look?

I started by calling the general information number for the State and described my son's needs and was given the number for the Department of Human Services, who in turn, referred me to the Department of Health's Developmental Disability Division (DOH-DDD). We then immediately pursued getting a case manager with the DOH-DDD and Tom began attending an adult waiver program at an agency.

For two years everything went fairly well until the company I worked for left the island. When I

went looking for work I could not find employment that fit with Tom's schedule. At that time Tom's agency case manager told us about a state program that paid parents of adult children for chore services. We were registered and I



Thomas

was paid minimum wage for taking care of Tom's home; cleaning, cooking, laundry, and running errands for him. For the next four years we maintained a very meager lifestyle.

At the same time I also contacted the State Developmental Disabilities Council for information. Through the Council I learned of legislation that was being considered that would allow parents of adult children to be paid as a Personal Assistant for their adult child. I closely followed the legislation, and the day after the legislation was enacted, I contacted our DOH case manager and told him that I wanted to become my son's Personal Assistant. Our case manager referred me to an agency and I went through their hiring process.

Now I am employed full time, and the agency provides me with a 401K plan and health care insurance including medical, vision and dental services. As my son Tom says, "NOW WE HAVE A LIFE"!

MOLOKAI SITE COUNCIL



Natalie

Natalie shared something she learned as she developed her life plan:

FIRE = Freedom, Independence, Responsibility, Excellence

- Freedom to choose like choosing MOC or ARC. (Molokai Occupational Center/ ARC of Molokai)
- Independence like living with who you want to live.
- Responsibility to be in charge of your money.
- Excellence - doing your best like Benny, my Case Manager.

The CPASS grant is part of President Bush's New Freedom Initiative, and is awarded to the Department of Health Developmental Disabilities Division and administered by the University of Hawaii's Center on Disability Studies (CDS). Sandra Kofel of CDS is the grant coordinator and Wil Young is the DOH-DDD administrative liaison.

www.hawaii.gov/health/disability-services

[/developmental/cpass-grant/](http://developmental/cpass-grant/)

CPASS SUMMIT 2005



CPASS HAWAII



Leeward Oahu



Molokai



East Hawaii



Statewide

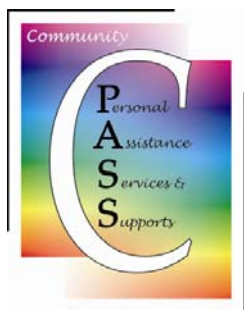
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Alternative formats available



Working for a System of Responsible Choice & Participation

CPASS envisions a **system** where people with developmental disabilities and their families have **choice, flexibility, and control** over their **personal assistance services**, and are supported to be **safe, successful, and independent**.

The CPASS Demonstration Project!

The CPASS Demonstration Project is an opportunity to put some of the ideas and service delivery models we have been learning about into practice. The project will help everyone learn more about planning and delivering consumer directed services. We believe this project will have a positive impact in the lives of self-advocates, with the results benefiting all self-advocates in Hawaii.

The CPASS grant project sites of East Hawaii, Leeward Oahu and Molokai are in the process of identifying participants who will take an active part in the demonstration project. One important support initiative being explored is the concept of a "Community Support Guide" (CSG) that will assist project participants in achieving their stated goals. The Community Support Guide has a different role from a Case Manager or a Personal Assistant. Things a CSG should do include:

- Help individuals achieve one or more of their goals
- Increase individuals' personal networks – build relationships; meet people who may be able to help
- Find existing community resources that can help with individuals' goals
- Be creative and develop resources and find funding if needed

Together we can help everyone follow their dreams.